



General Assembly

January Session, 2019

Raised Bill No. 7282

LCO No. 4878



Referred to Committee on PUBLIC HEALTH

Introduced by:
(PH)

AN ACT CONCERNING NEWBORN SCREENING FOR SPINAL MUSCULAR ATROPHY.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the general statutes is repealed and the
2 following is substituted in lieu thereof (*Effective October 1, 2019*):

3 (a) The administrative officer or other person in charge of each
4 institution caring for newborn infants shall cause to have administered
5 to every such infant in its care an HIV-related test, as defined in section
6 19a-581, a test for phenylketonuria and other metabolic diseases,
7 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine
8 disease, homocystinuria, biotinidase deficiency, congenital adrenal
9 hyperplasia, severe combined immunodeficiency disease,
10 adrenoleukodystrophy and such other tests for inborn errors of
11 metabolism as shall be prescribed by the Department of Public Health.
12 The tests shall be administered as soon after birth as is medically
13 appropriate. If the mother has had an HIV-related test pursuant to
14 section 19a-90 or 19a-593, the person responsible for testing under this
15 section may omit an HIV-related test. The Commissioner of Public

16 Health shall (1) administer the newborn screening program, (2) direct
17 persons identified through the screening program to appropriate
18 specialty centers for treatments, consistent with any applicable
19 confidentiality requirements, and (3) set the fees to be charged to
20 institutions to cover all expenses of the comprehensive screening
21 program including testing, tracking and treatment. The fees to be
22 charged pursuant to subdivision (3) of this subsection shall be set at a
23 minimum of ninety-eight dollars. The Commissioner of Public Health
24 shall publish a list of all the abnormal conditions for which the
25 department screens newborns under the newborn screening program,
26 which shall include screening for amino acid disorders, organic acid
27 disorders and fatty acid oxidation disorders, including, but not limited
28 to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and
29 medium-chain acyl-CoA dehydrogenase (MCAD).

30 (b) In addition to the testing requirements prescribed in subsection
31 (a) of this section, the administrative officer or other person in charge
32 of each institution caring for newborn infants shall cause to have
33 administered to (1) every such infant in its care a screening test for (A)
34 cystic fibrosis, [and] (B) critical congenital heart disease, and (C) on
35 and after January 1, 2020, spinal muscular atrophy, and (2) any
36 newborn infant who fails a newborn hearing screening, as described in
37 section 19a-59, a screening test for cytomegalovirus, provided such
38 screening test shall be administered within available appropriations.
39 [on and after January 1, 2016. On and after January 1, 2018, the] The
40 administrative officer or other person in charge of each institution
41 caring for newborn infants who performs the testing for critical
42 congenital heart disease shall enter the results of such test into the
43 newborn screening system pursuant to section 19a-53. Such screening
44 tests shall be administered as soon after birth as is medically
45 appropriate.

46 (c) The administrative officer or other person in charge of each
47 institution caring for newborn infants shall report any case of
48 cytomegalovirus that is confirmed as a result of a screening test
49 administered pursuant to subdivision (2) of subsection (b) of this

50 section to the Department of Public Health in a form and manner
51 prescribed by the Commissioner of Public Health.

52 (d) The provisions of this section shall not apply to any infant whose
53 parents object to the test or treatment as being in conflict with their
54 religious tenets and practice. The commissioner shall adopt
55 regulations, in accordance with the provisions of chapter 54, to
56 implement the provisions of this section.

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| This act shall take effect as follows and shall amend the following sections: | | |
| Section 1 | <i>October 1, 2019</i> | 19a-55 |

Statement of Purpose:

To require newborn screening for spinal muscular atrophy.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]